

**Important Life Dimensions for Self-Advocating People with Intellectual  
Disabilities in the South-East Region of the Republic of Ireland.**

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Over the past number of years Irish society has witnessed significant political, social and economic change with increased prosperity, improved infrastructures and a general increase in the wealth of the nation (Nolan et al 2000). This national growth has been accompanied by improvements in many aspects of life for Irish citizens, but, however, within this growth it has emerged that there is evidence to suggest a corresponding societal increase in inequality, marginalisation, exclusion and polarisation (Nolan et al 2000). Social inclusion means being in a position to participate fully in the life of the society one lives in, conversely, social exclusion entails being prevented from doing so.

Disability is defined as – the loss or limitation of opportunities that prevent people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers (Finkelstein and French 1993). People with disabilities face many barriers to full participation, and are thus likely to face a heightened risk of social exclusion across various dimensions (Gannon and Nolan 2005). In reporting on disability and social inclusion in Ireland, Gannon and Nolan (2005) reported that in recent years there has been a major shift in the assumptions held about the nature of disability, away from the ‘medical model’ of disability towards what has been termed a ‘social model’. The underlying assumption of the medical model, was, that people with a disability were different from the norm and needed to be helped or cured. The central shift in thinking toward the social model was that disablement arose from the environment and organisation of society rather than from the individual and their impairment. Disability is seen as a consequence of social, attitudinal and environmental barriers that prevent people from participating in society. The focus is then on the need to change societal conditions to accommodate the needs of the disabled person to participate in such activities as education, employment and leisure. According to the National Disability Authority (NDA) (2003) the 1990’s and onwards marked significant change in disability legislation and policy with cumulative efforts to promote and help secure the rights of people with disabilities, and to promote information and advocacy for people with disabilities and others.

The disability movement has been working towards community participation and inclusion (Nolan et al. 2000). Despite this, evidence suggests that many people with intellectual disability live isolated marginalized lives without access to the support and services required to improve their quality of life (Gannon and Nolan 2005). These people have a right to play a full part in society and have their wishes heard and met, but too often they are socially excluded and have decisions made for them (Morgan 2002).

McCarthy (1998) suggests that the best way of increasing our knowledge of how people with intellectual disability experience their lives is to speak with people who have intellectual disability.

Interviewing people with intellectual disability is suggested as a promising way forward, deepening understanding of the impact of living with such a powerful identifying label, and informing the way services support and empower people with intellectual disability (National Disability Authority 2009, Department of Health 2005). It enables and empowers people with intellectual disability and opens the space for them to communicate their life dimensions and things that are important to them.

This study aims to answer the following research question – What are the important life dimensions for self-advocating people with intellectual disabilities in the south east region of the Republic of Ireland? More specifically, in answering this question, the proposed study, employing an inclusive approach will:

- Identify these individuals' important life dimensions
- Establish what services are in place to support these life dimensions
- Identify what services would be considered necessary to support these life dimensions.
- Report and make recommendations to the services and appropriate authorities.

In reviewing the literature on intellectual disability, Beart et al (2005) posited that inclusive research in this area gives valuable insights applicable to people with intellectual disability. The research is relevant to the people with intellectual disability and beneficial in terms of delivering meaningful outcomes for the participants and the population they represent. A participative action research approach involves people with intellectual disability in the research allowing for a subjective approach relating to life dimensions in these peoples' lives (Walmsley and Johnson 2003). The principles and characteristics upon which inclusive research is based are as follows; the research must address issues which really matter to people with intellectual disabilities, and which ultimately leads to improved lives for them; it must access and represent their views and experiences; people with intellectual disability need to be respected by the research community; the research question is owned by disabled people; it is collaborative – disabled people involved in doing the work; and some control is exercised by disabled people over process and outcomes.

Therefore, it seems appropriate to address this deficit by undertaking a study that will evaluate and report on the subjective experiences relating to the important life dimensions of self-advocating people with intellectual disability. This study will employ a participative action research design concerned with freeing the voices of people with intellectual disability enabling a consideration of their life experiences, and putting these in the context of the broader dimensions of their lives.

Participatory action research enables people with intellectual disability to work in partnership with researchers and to have greater influence over the process of the research, and furthermore, it empowers them in learning new skills and is holistic in nature (Walmsley and Johnson 2003, Priestly 1995). Participatory action research highlights a shift from doing research on and about populations of people with intellectual disability to doing research with these populations. Involving people with intellectual disability in an appropriate way respects them as active participants in the research process and not as passive objects of research.

Phase 1 of this proposed study involves the inclusive and participatory selection of the research group. Having discussed, decided and agreed on the research foci and methodology, it is intended for the group to return to the Faculty of Health Sciences Research Ethics Committee Trinity College Dublin, and the Research Ethics Committee, H.S.E. South East before proceeding with Phase 2 – carrying out the research.

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